

Purpose

The purpose of this Bridge Brief is to describe family and child-centered services within a medical home.

Summary

Medical homes are rural clinics that adopt a philosophy of practice that respects and honors families as central to all services provided to children with special health care needs (CSHCN). A medical “home” is not a physical place where families reside, but rather, a “home-base” within the community—a location where families can be connected to community supports and services for their children.

Implications

Although all children rely on their families for ensuring their health, development, and overall well-being, for CSHCN the role of the family is even more critical. A medical home model of service delivery can improve the services children and families receive.

Family Participation within the Medical Home

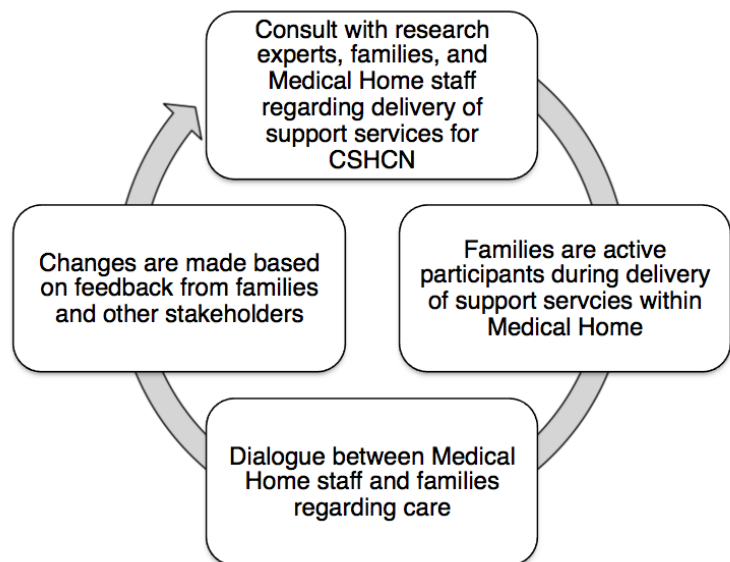
Jody Marie Pirtle, Ph.D.

Introduction

Children with Special Health Care Needs (CSHCN) are children with chronic physical, developmental, emotional, or behavioral conditions who need or use health and related services of a type or amount beyond that typically required by children (McPherson et al., 1998). The original Medical Home concept was introduced by members of the American Academy of Pediatrics in 1967 but was substantially updated by 2002. Medical professionals around the country have only begun to adopt the concept of medical homes in their clinics. The medical home refers to a clinic that uses a child- and family-centered approach to deliver services. Medical professionals who deliver these family-centered services, consider all family members’ strengths and needs as they work with the family to assist them in making informed decisions about services and supports their CSHCN may require (Kovacs, Bellinb, & Fauria, 2006).

In a medical home, families’ participation consists of feedback to the medical home staff about the families’ and children’s needs, care coordination experiences, personal goals, and medical care satisfaction. The medical home professionals use the families’ input to inform systematic changes or parent education program development in the medical home. Feedback and subsequent efforts to improve services remain in a continual improvement cycle ensuring families are involved in all aspects of the medical home services (CMHI, 2001).

Figure 1. Continual improvement cycle within the medical home



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Best Available Evidence

CSHCN and their families are integral in all decisions made within the medical home including the methods used to study them. Community-based participatory research (CBPR) is a process whereby researchers and stakeholders who potentially benefit from the research results collaborate in the design of the research process (Turnbull, Friesen, & Ramirez, 1998). The CBPR approach is consistent with the philosophy of medical homes and helps to ensure families receive the best services possible. Anderson (2009) found that mothers of CSHCN who received services within a medical home noted (a) improved communication between professionals and families, (b) their concerns with educational systems and personnel were addressed, (c) feeling confident as 'experts' in their children's care, and (d) having more coping strategies.

In a medical home, service providers can improve the quality and cohesiveness of the children's health care services by helping to foster and maintain communication between families, health care professionals, and specialists (AAP, 2002). When children's health care services are coordinated, families feel more comfortable working with professionals because professionals are "on board" with what families expect from medical interventions. Family-centered approaches to health care interventions also lead to wiser allocation of health care resources in general, as well as greater patient and family satisfaction.

Implications

Collaboration between parents, medical professionals, educators and community members is at the core of all medical homes. Creating a medical home takes commitment, hard work, and dedication from all vested mem-

bers. Medical professionals interested in the shift from traditional service delivery models to the medical home model must address families' support and service needs and pool resources to provide all children accessible, continuous, comprehensive, and family-centered health care they deserve. The process of medical care can be more effective and efficient if professionals seek input from the most valuable stakeholders, families of CSHCN.



Resources

What is a medical home?

<http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedical-Home/whyimportant.html>

National Center for Medical Home Implementation

<http://www.medicalhomeinfo.org/>

About the Author

Jody M. Pirtle, Ph.D. is an Assistant Clinical Professor at Northern Arizona University. Her major at the University of Arizona was Special Education with an emphasis on young children with severe and/or multiple disabilities, including autism. Her minor was Family Studies and Human Development. As a former special educator, she was instrumental in collaborating with community members and professionals to design and deliver family-centered interventions within a medical home in rural Arizona.

References

- American Academy of Pediatrics (2002). *Policy statement: Organizational principles to guide and define the child health care system and/or improve the health of all children. Pediatrics, 110(1), 184-186. doi: 10.1542/peds.110.1.184*
- Anderson, L. S. (2009). *Mothers of children with special health care needs: Documenting the experience of their children's care in the school setting. The Journal of School Nursing, 25, 342 – 351. doi: 10.1177/1059840509334146*

Center for Medical Home Improvement (CMHI, 2001). *Building a Medical Home, Lebanon, NH: Hood Center for Children and Families, Children's Hospital at Dartmouth-Hitchcock Medical Center*

Kovacs, P., Bellinb, M., & Fauria, D. (2006). *Family-centered care, Journal of Social Work in End-Of-Life & Palliative Care, 2(1), 13 – 27.*

McPherson M., Arango P., Fox H., Lauver C., McManus M., Newacheck P., Perrin J., Shonkoff J., & Strickland B. (1998). *A new definition of children with special health care needs. Pediatrics, 102(1), 137 - 140.*

Turnbull, A. P., Friesen, B. J., & Ramirez, C. (1998). *Participatory action research as a model of conducting family research. Journal of the Association for Persons with Severe Handicaps, 23(3), 19-26.*



Bridge Briefs are a publication of the Institute for Human Development (IHD). The IHD is a research and training program located at Northern Arizona University and part of a national network of University Centers for Excellence in Developmental Disabilities (UCEDD).

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